

Staying well with IBD

Introduction

If you have Inflammatory Bowel Disease (IBD), which includes Crohn's disease and Ulcerative Colitis (UC), your symptoms are likely to come and go. It is a very individual condition with some people remaining well for a long time, even for many years, while others have frequent flare-ups. Living with a long-term illness can affect you physically and emotionally. This information sheet looks at factors that may help you to stay well more of the time.

Understanding

It can be a shock to hear that you have a chronic illness. No-one can tell you with certainty what causes it or how your disease will develop. Not knowing what to expect can leave you feeling helpless and uncertain. Many with IBD find that the more they learn about the condition and how to manage it, the more they feel in control of their lives. Of course everyone is different and how much detailed information you wish to know will be your choice.

NACC has a range of publications, an information line, a list of books on all aspects of IBD and a newsletter to inform and to keep you up-to-date with research and new treatments.

Acceptance

It is common to feel angry and upset or depressed about being diagnosed with a disease, wondering what it will mean to you. Some people initially respond by being in denial or by being totally overwhelmed. While no-one can pretend it is easy coming to terms with an illness, accepting that you have a medical condition can help you to keep a balance in your life. There may be times when you need to make adjustments. During a flare-up for example, take time to rest and

recuperate, rather than rushing back to work or doing daily chores. On the other hand when you do feel well you can make the most of your time. Despite the impact that IBD can have on everyday living, many people with the illness do well in their studies and are able to work full-time.

Part of accepting your illness means telling your family, friends and colleagues. Although it may be embarrassing at first, it will give you less to worry about and help you to share your anxieties and problems. NACC has a booklet: *Living with IBD* with suggestions on how to explain your IBD to others. NACC also has a leaflet they might find useful: *When someone in your family has IBD*.

Talking to your healthcare team

Having IBD means that you are likely to see your GP and specialist doctor or nurse more frequently than other people and it is important that you build up a good relationship. Talking to them openly about your symptoms and how you feel helps them to understand your needs. Health professionals expect patients to ask questions, so don't be afraid to ask all you want to know about medication or tests or query anything you do not understand about what they have said. It may help to ask a family member or friend to attend appointments with you. Taking a list you have prepared beforehand of what you want to say and taking notes during and after the session about what has been said will help you to remember. The NHS leaflet 'Questions to ask' has some useful suggestions and you can call the NACC Information line for a copy or download it from: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079531.

Taking medication

You will usually be prescribed medication when you are first diagnosed to control your symptoms. Once you feel better, you may want to stop taking your medication, thinking you don't need it. You may feel fed up with taking pills or worried about their side effects. You may also feel that taking regular medication reminds you that you have a disease.

While these are understandable concerns, many studies have shown that maintenance therapy, which means continuing to take medication even when you are well, helps to prevent flare-ups. If you have Crohn's disease this may be an immunosuppressant, such as azathioprine (also sometimes called an immunomodulator); in UC the 5-ASA anti-inflammatory drugs have been found effective in reducing relapses. (See NACC's booklet *Drugs used in IBD* for more details). Generally it is easier to keep IBD under control with medication than to get it under control when it flares up. Taking regular anti-inflammatory drugs may also reduce the need for courses of steroids and may also reduce the slightly increased risk of bowel cancer that some people with IBD may have. (See NACC's leaflet: *Is there a risk of cancer in IBD?* for more details.)

It can be a problem remembering to take your medicine, especially when you are feeling well. Try to make taking it a part of your daily routine, for example at mealtimes or when brushing your teeth. Other tips that may help:

- Keep a weekly timetable, listing all your medication and when you need to take it. Tick off the dose once you have taken it.
- Keep your medicines where you will see them when you need to take them. This could be near your toothbrush if you have linked them with brushing your teeth; or in the kitchen if you have linked them with mealtimes.

- Put notes on the bathroom mirror, fridge or television. It might be helpful to change the wording, colour and location frequently, so you don't become 'blind' to them.
- If you use your computer regularly, you could set up a reminder note to appear every time you start up.
- Use alarms on your watch, clock or mobile phone. You can also buy Medication Alarms from chemists or via the internet. You can obtain a list of suppliers from the Disabled Living Foundation (see *Further help* below).
- Store your pills in a dosette box which organises them into compartments by time and day. These are available at chemists or online.
- Put a laminated reminder card on the back of your front door to remind you to take your medication with you when you are going out.

It is a good idea always to have a good supply of your medication, particularly when you are planning to be away from home.

If you have any doubts about your medication or get upsetting side effects, talk to your GP, specialist doctor or IBD nurse, as there may be an alternative you can take. See NACC's leaflet: *Taking medicines for IBD*.

If you do feel a flare-up starting, the earlier you act the easier it is likely to be to bring it under control. It helps to learn the patterns of your disease and the signals of an oncoming flare-up. When you get those symptoms, contact your doctor or nurse to find out what you need to do. You may have already set up a plan with your specialist to increase your medication when symptoms appear. Taking an active role in your medical care helps you to feel more in control.

Taking care of yourself

If you are taking certain drugs, such as steroids and immunosuppressants, you could be more vulnerable to catching infections. This is because these drugs lower your immune system.

Try to avoid people with coughs, colds, flu etc. Health professionals strongly recommend having an annual flu vaccine.

To help avoid gastrointestinal infections be particularly careful with hygiene when preparing and cooking food. Be careful too when travelling abroad, where there may be a greater risk of food and water-borne infection. See NACC's leaflet: *Travel and IBD*.

If you have left-sided colitis, you should avoid constipation, which is known to trigger flare-ups. A diet that includes a moderate amount of fibre, with an adequate intake of fluids, helps to maintain a regular bowel habit.

If you need to take any over-the-counter medicines, avoid non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen and diclofenac: they may trigger a flare-up. Paracetamol is safer, although doctors recommend that you do not exceed the recommended daily limit of 8 standard (500mg) tablets per day nor use this medication continuously without medical advice.

Getting plenty of rest and sleep is also important to help keep your mind and body healthy.

Healthy eating

Everyone knows the importance of eating a nutritious balanced diet to keep healthy. Having IBD you may find this more difficult. Certain foods may affect you, particularly with Crohn's disease, and you may need to avoid them. In UC high-fat foods can trigger diarrhoea. If you have Crohn's, depending on the area of your disease, you may also have difficulty absorbing minerals and vitamins. It is then particularly important that you eat enough from all the food groups to avoid being undernourished. You may also

need to take nutritional supplements to make up for any deficiencies.

Taking enough fluids is also important for health. It is more common for people with IBD to become dehydrated. See NACC's leaflet: *Dehydration*. If you have an ileostomy, maintaining your fluid balance may be more difficult. With a high output you may lose a lot of fluids, sugars, salt and potassium. You could contact the NACC Information Line or the IA (See *Other Organisations* below) for more details.

Some people with Crohn's take special liquid feeds called elemental or polymeric diets as treatment, though not everyone is able to tolerate them. Recent research has found that people with Crohn's taking these diets as long-term supplements had fewer relapses. It is not yet fully understood why, but some suggest it may be due to a higher-energy protein and carbohydrate intake together with a lower fat intake, as those in most of the studies were asked to eat a low-fat diet.

Other recent research has been on the use of particular supplements to help maintain remission in Crohn's disease – the times when you are generally free of symptoms. In some studies those with Crohn's taking a daily supplement of enteric-coated omega-3 kept well for longer. However, these studies were small and in two larger studies omega-3 was not found effective in preventing relapses.

Another area of research is on how pre- and probiotics may improve IBD by changing the balance of bacteria in the colon (large bowel). The colon contains billions of bacteria: some may be good for our health and others harmful.

Prebiotics are carbohydrates that stimulate growth of potentially good bacteria in the gut and can be taken as supplements. They have to be taken continuously to maintain their effectiveness, but research cannot yet tell if they are helpful in IBD.

Probiotics are 'friendly' bacteria, which are taken as supplements to increase the good bacteria already in the colon. They may help to keep you healthy if you have UC that is not active or when using antibiotics. If you have had surgery for UC and have had pouchitis, probiotics with high concentrations of particular bacteria can help to prevent a relapse.

More research needs to be done in all these areas, but you could discuss these supplements with your GP, specialist or a dietitian.

It is important to get specialist help for advice on diet, particularly if you have Crohn's. Diet is much less of an issue in UC. You can ask your specialist to refer you to a dietitian on the NHS or contact The British Dietetic Association to find a dietitian (see *Other Organisations* below). For more details on diet see NACC's booklet: *Food and IBD*.

Stop smoking

If you have Crohn's disease and are a smoker, one of the most important factors for better health is to stop smoking. Your Crohn's is likely to be more severe and you are more likely to require surgery if you smoke.

The situation is different in Ulcerative Colitis. Some people have developed UC when they gave up smoking. Of course that is not to say that you should take up smoking, as this would put you at risk of cancer, heart and lung diseases. See NACC's leaflet: *Smoking and IBD*.

Reducing stress

While stress is not a cause of IBD, too much may lead to a flare-up. Stress is a part of life, but how you deal with it can make a difference to your well-being. Becoming aware of what is causing you stress is the first step in tackling it. Life events such as moving, getting married/divorced, bereavement, work problems, redundancy, a new job, family gatherings, etc are likely to make you more stressed. Some ways to help you reduce stress include:

- Make time for relaxation or leisure each day. Try deep breathing and deep muscle relaxation exercises, aromatherapy, reflexology or yoga.
- Take time to eat your meals. Sit down and eat slowly, allowing at least half an hour for each meal.
- Exercise regularly. See *Taking exercise* below.
- Be realistic about what you can achieve. Don't take on too much – learn to delegate.
- Don't feel guilty about saying 'no'.
- Set priorities – if you could only do one thing, what would it be?
- Plan ahead for anything that you know causes you stress.
- Don't make too many changes in your life all at once.
- Take regular holidays. Just a change of surroundings over a long weekend can be as good as a long holiday.
- Talk things over with a friend or family member or someone else you can trust and share your feelings with. Even writing down your feelings in a journal or on a blog or website discussion board can help.

If you find it difficult to overcome stressful feelings, you may find it helpful to see a counsellor. NACC has given specific training on IBD to qualified counsellors. For more details contact the NACC Information Line. Your GP may have a counselling service or you can find a counsellor through the British Association for Counselling and Psychotherapy. See *Other Organisations* and NACC's leaflet: *How can counselling help you?*

Taking exercise

You may feel that exercising is the last thing you want to do. You may feel too tired; you may be worried that it will make your IBD worse or you may fear having

an 'accident'. While adequate rest is essential, being inactive for too long can lead to a number of problems such as muscle weakness and stiff joints. It can also make you less motivated and have difficulty concentrating.

Regular exercise will improve your overall health, keeping your body functioning well. It can help to relieve the fatigue which is common in IBD. Physical activity also helps to strengthen bones, which is particularly important as there is the risk of thinning of the bones (osteoporosis) in IBD. See NACC's leaflet: *The bones and IBD*. You could also contact the National Osteoporosis Society (see *Other Organisations*).

Besides keeping your body in shape and possibly helping you to avoid other problems, regular exercise also helps you psychologically. Exercise is known to release endorphins, the chemicals in the brain that give you a sense of happiness and act as natural pain killers.

If you are not used to regular exercise, you could begin with a short walk several times a week and then gradually increase the times and distance you walk. Just getting out of the house into the fresh air can help you to feel more positive. While any activity can make people want to open their bowels, taking exercise will not worsen your IBD. You can set your own pace to build up your confidence. It is sensible to talk to your doctor or specialist nurse before starting any strenuous exercise.

Getting support

Having support is important for everyone and especially so if you are living with a long-term illness. It can make all the difference in coping with illness and to your quality of life. Living with an ongoing condition can put a strain on relationships with partners, family and friends. You may sometimes feel that no-one around you understands what it means for you to live with IBD. Those close to you are more than likely to want to help you, but they may not know how. Being open with them about your feelings and giving them

information to read about IBD helps them to understand.

You may also find it helpful to join a local IBD group for mutual support. NACC has many groups around the UK and you could contact the NACC information line or look on the NACC website to find out if there is a group near you.

If it is difficult for you to attend meetings, you could be in touch with others with IBD through website discussion boards.

There may be times when you feel isolated, upset or want to talk about a problem and just having a 'listening ear' would help. NACC provides a supportive confidential listening service called NACC-in-Contact. See details below.

Being positive

Managing your condition in the ways suggested here is likely to make you feel more positive. There will of course be days when you feel down and that life is not fair. It would be unusual if you never felt that way, but don't lose sight of your achievements and the times you have coped. You don't have to expect too much of yourself, but the more you look after yourself, the more you will be able to enjoy your life.

Further help

If you have any further queries or would like copies of NACC publications mentioned please call the **NACC Information line** on **0845 130 2233** or email: nacc@nacc.org.uk Leaflets can also be downloaded from the NACC website: www.nacc.org.uk

NACC also provides a website discussion forum, **IBD and Me**, for 16-29 year olds with IBD: www.ibdandme.org.uk

To speak to a NACC Contact please call **NACC-in-Contact** on **0845 130 3344** **weekday afternoons 1-3.30pm and evenings 6.30-9pm.**

Contacts are volunteers trained in supportive listening who have IBD or a relative with IBD.

Other Organisations

British Association for Counselling and Psychotherapy

BACP House, 15 St John's Business Park, Lutterworth LE17 4HB

☎ 01455 883300

Email: bacp@bacp.co.uk

Website: www.bacp.co.uk

Disabled Living Foundation,

380-384 Harrow Road, London W9 2HU

Tel: 020 7289 6111

Helpline: 0845 130 9177

Weekdays 10am-4pm

Email: info@dlf.org.uk

Website: www.dlf.org.uk

IA

The Ileostomy and Internal Pouch Support Group

Peveill House, 1-5 Mill Road, Ballyclare, Co Antrim, BT39 9DR

☎ 0800 018 4724 (freephone) or
028 9334 4043 (standard rate)

Email: info@iasupport.org

Website: www.iasupport.org

National Osteoporosis Society

Manor Farm, Skinners Hall, Camerton, Bath, BA2 0PJ

☎ Helpline: 0845 450 0230

Mon-Fri 9am-5pm – to speak to a nurse

Email: info@nos.org.uk

Website: www.nos.org.uk

The British Dietetic Association

5th Floor, Charles House

148/9 Great Charles Street

Queensway, Birmingham B3 3HT

Tel: 0121 200 8080

Email: info@bda.uk.com

Website: www.bda.uk.com

Further reading

Living a Healthy Life with Chronic Conditions 2nd Edition by K Lorig.

Bull Publishing Co. 2000.

ISBN 0-923521-53-4

Living with a long-term illness: The Facts by Frankie Campling & Michael Sharpe
OUP. 2006. ISBN 0-19-852882-1

Learning Sickness: A Year with Crohn's Disease by James M Lang.

Capital Books Inc. 2004.

ISBN 1-931868-60-3

The Stress Workbook by Joanna

Gutmann. Sheldon Press. 1998.

ISBN 978-0-85969-787-3

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We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. Please send your comments to Helen Terry at NACC, 4 Beaumont House, St Albans, Herts AL1 5HH – or email h.terry@nacc.org.uk

The National Association for Colitis and Crohn's Disease (NACC) is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcomed.